Paper #3 in the Series: "Should Montana Have a Public Policy on Sterilization of Those Involved in Mental Retardation and If So, What Should It Be?"

"A Survey of Sterilization Legislation in 17 States"

The Montana State Developmental Disabilities Planning and Advisory Council has researched the issue of sterilization policy for over a year. As a final step, Council staff surveyed the 17 states that have sterilization legislation which includes safeguards of the person's rights (see list--Appendix A).

The Council wanted to learn the following:

1. What groups sponsored and supported the legislation?

2. What arguments were important in persuading legislators to support the legislation?

3. What groups opposed the legislation and what were their arguments or major points?

4. What are the major provisions of the law, including how sterilization of minors is treated? and

5. Has the law been successful?

Of the 17 states polled, 16 sent copies of their legislation. The dates of the legislation range from 1970 to 1986 (see list--Appendix A).

Ten states responded to Question #1 (What groups sponsored and supported the legislation?). The state Association of Retarded Citizens (ARC) sponsored legislation in six states and the state mental retardation division in five (along with the ARC in several cases). In CO the State Bar Association sponsored the legislation and in DE, the state protection & advocacy group. In four states a coalition of other interested groups supported the legislation (see Table #1 on page 2).

Table #1

Question #1: What groups sponsored and supported the legislation?

State ARC	State Mental Retardation Division	Other
CA	CA	CA (United Cerebral Palsy Assoc., Assoc. of Regional Center Agencies, ACLU, State DD Planning Council, State Protection & Advocacy group, and Capitol People First, Inc.--a consumer group)
	GA	CO (State Bar Assoc.)
	ME	DE (State Protection & Advocacy group)
MN	MN	MN (State DD Planning Council, State Protection & Advocacy group)
OR		
VT		
VA		VA (ACLU)
WV		WV (Task Force of attorneys & judges whose primary purpose was to revise the Criminal Code; they decided the sterilization law needed revising too.)

In answer to Question #2 (What arguments were important in persuading legislators to support the legislation?), the California ARC stated that "access to sterilization is fundamental for certain persons with developmental disabilities in order to assure their ability to exercise basic rights such as the right to associate with the opposite sex....inability to have access to sterilization can be more restrictive and injurious to an individual's life than the sterilization itself."[1]

Consensus among the other states responding (GA, ME, MN, OR, VT, WV) was that no legislation denied the choice of being sterilized

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[1]Analysis by California Senate Judiciary Committee (Bill Lockyer, Chair), 1985-86 Regular Session, page 3.

to persons with developmental disabilities and that safeguards and procedures should be clearly spelled out in law to ensure due process.

In response to Question #3 (What groups opposed the legislation and what were their major arguments?), five states recalled no opposition (GA, MN, OR, VT, WV). Maine reported no unified opposition, but the Department of Mental Retardation worked with the State Medical Association and the Roman Catholic Church to deal with some concerns.

In California, a very active consumer group, Capitol People First, Inc., raised a number of concerns. These included the following:

1. not limiting the bill to persons with developmental disabilities because they felt that was discriminatory. The group suggested striking all references to developmental disabilities and simply referring to persons who, for whatever reasons, are unable to make voluntary decisions; and

2. including guidelines to make sure that sterilization isn't done to a person who will someday grow into the ability to make his or her own decisions about reproduction. People First wanted the law to mandate an intensive education and training period (2hrs/week for 17 consecutive weeks) to make sure the person wasn't capable of learning to make his or her own decision about sterilization.

Regarding the first concern, supporters decided not to change language to make the bill all-encompassing because they felt that different issues were involved, as for instance the question of permanency of disability with mental health. The intent of People First's second concern is part of the CA law in the following language: "The ...(respondent's) prior education and training would be considered to determine if he or she could, through additional education, become capable of giving informed consent."

That the legislation did pass in California with a large coalition of supporters including this very active consumer rights group is due in large part to the fact that "sponsors made extraordinary efforts to include, involve and address all points of opposition prior to the bill's introduction and continued to do so throughout the legislative process."[2]

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[2]Letter to Louisa Schultz from Ellen Fishman, Staff Analyst, CA Council on DD, July 28, 1987.

As to the specific provisions of the laws, a composite of statutes from AR, CA, CT, DE, GA, ID, ME, MN, OR, VT and VA follows (see also Appendix C and Appendix D):

1. Guardian (or similar person) petitions the court for sterilization on behalf of the respondent.

2. Notice of the hearing is given.

3. Guardian ad litem is appointed for the respondent and independent counsel which acts on the presumption that the respondent opposes the petition.

4. The court orders a medical, psychological, and sociosexual evaluation by a medical doctor and a psychologist or psychiatrist to determine the following:

   a) that the respondent is incapable of giving consent to sterilization and that the incapacity is, in all likelihood, permanent (i.e., the person will not become capable of informed consent in the foreseeable future);

   b) that the respondent is fertile and capable of reproduction and is incapable of caring for and raising a child; and

   c) that the current state of scientific and medical knowledge does not suggest that reversible sterilization or less drastic contraceptive methods will shortly be available or that science is on the threshhold of an advance in treatment of the person's disability.

In addition to the evaluating team's report, the court will hear evidence from the petitioner(s) that sterilization is in the respondent's best interest, an assertion satisfied by meeting criteria such as the following:

1. Respondent is now or is likely soon to be sexually active, and pregnancy would not usually be intended by a person without disabilities under the same circumstances.

2. Respondent would suffer severe physical or mental harm if he or she were to parent a child.

3. Less permanent contraceptive methods are unworkable, inapplicable or medically contraindicated.

4. The proposed method of sterilization is the least intrusive and can be carried out without unreasonable risk to the life and health of the respondent.

5. Respondent has not voiced any objection to being sterilized.

6. The petitioners are seeking sterilization in good faith and their primary concern is for the best interests of the respondent rather than their own convenience.

If the court decides the evidence is clear and convincing that sterilization is in the respondent's best interest, it will issue a court order. The respondent has 30 days to appeal the order before it can be carried out (in WV, respondent has 60 days). At any time, regardless of the findings of the court, the respondent may refuse the sterilization.

The CA law requires the Department of Developmental Services to file an annual report with the appropriate legislative policy committee on the number of petitions filed and their resolution. This provision will enable the state to evaluate the law's effectiveness.

Regarding the question of treatment of minors in the legislation, seven states permit such sterilization with guidelines, four do not, and four laws don't address the issue (see Table #2).

Table #2

Question #4: How is sterilization of minors treated in the legislation?

Permitted Over Age 14	Not Permitted	Not Addressed in Law
AR	CA	CO (3)
GA	CT	DE
ID (1)	OR (2)	MN
KY	VT	WV
ME		
UT		
VA		

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(1) law applicable past the age of puberty.

(2) does not permit court-ordered involuntary sterilization; those aged 15-18 may, however, give informed consent.

(3) but CO Supreme Court held that state courts do have jurisdiction over the sterilization of minors.

And finally, regarding the question of how successful these laws have been, the consensus is that, in the relatively small number of cases that come up, they are doing what state legislatures intended:

1. providing a choice for those persons with disabilities who cannot consent directly;

2. providing strict procedures and guidelines to ensure due process through the courts and to ensure sterilization in the best interests of the respondent;

3. providing ample opportunity for the respondent to voice his or her own feelings about sterilization, away from any real or potential family pressure, to the court appointed evaluation team, to the guardian ad litem, to counsel and to the judge; and

4. protecting people from inappropriate sterilization done for the convenience of their caregivers or so that foul practices such as incest may continue without pregnancy.

Summary

The issue of whether or not to press for sterilization legislation is complex. On one side stand those strong proponents of the view that a constitutional right such as procreation should never be abridged for someone else. On the other side stand those who believe that having no legislation denies the right of choice to be sterilized to those who cannot directly consent (see Appendix E).

Based on the experiences of those states with a sterilization law providing stringent safeguards, it is clear that such a law offers the choice of sterilization to those lacking the capacity to give informed consent. In the absence of legislation, no clear choice exists.

Should groups in Montana such as the ARC or PLUK (Parents Lets Unite for Kids) decide to pursue the possibility of such legislation, the experience of California in particular clearly shows the efficacy of as broad-based a coalition of supporters as possible, including especially groups advocating for the rights of persons who are disabled. Those primarily responsible for the legislation should work actively with all interested groups throughout the legislative process so they can include, where

possible, the interests of opposing groups and allay that opposition. The resulting law will be fairer and more comprehensive for this effort.

Prepared by

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APPENDIX A

List of States Surveyed With Abbreviations Used Throughout the Report, Date of the Law and Whether DDPAC has a Copy

ARKANSAS	AR	1971	Yes
CALIFORNIA	CA	1986	Yes
COLORADO	CO	1975	Yes
CONNECTICUT	CT	1979	Yes
DELAWARE	DE	1985	Yes
GEORGIA	GA	1970/amended 1985	Yes
IDAHO	ID	1973	Yes
KENTUCKY	KY	1974	Yes
MAINE	ME	1982/amended 1984	Yes
MINNESOTA	MN	1981/amended 1985	Yes
NEW HAMPSHIRE	NH	1979	Yes
NORTH CAROLINA	NC	1974	No
OREGON	OR	1983	Yes
UTAH	UT	1983	Yes
VERMONT	VT	1982	Yes
VIRGINIA	VA	1982	Yes
WEST VIRGINIA	WV	1974	Yes

APPENDIX B

Knowledgeable Persons in Each State (For Future Reference)

AR NAN ELLEN EAST, Advocacy Services, Inc., 12th & Marshall, Suite 504, Little Rock, AR 72202 (501) 371-2171

SUSAN WALLACE, DD Services, 7th & Main, Suite 400, Little Rock, AR 72201 (501) 371-3419

CINDY HARTSFELD, DD Planning Council, 4815 West Markham, Little Rock, AR 72201 (501) 661-2589

CA ERIC GELBER, Protection & Advocacy, Inc., 2131 Capitol Ave., Suite 100, Sacramento, CA 95815 (916) 447-3324

ELLEN FISHMAN, State Council on DD, 1507 21st St., Room 320, Sacramento, CA 95816 (916) 322-8481

CO RANDY CHAPMAN, The Legal Center, 455 Sherman St., Suite 130, Denver, CO 80203 (303) 722-0300

CT LAWRENCE BERLINER, Office of Protection & Advocacy, 90 Washington St., Hartford, CT 06106 (203) 566-7616

DE BRIAN HARTMAN, Community Legal Aid, 913 Washington St., Wilmington, DE 19801 (302) 575-0110

GA CHARLES KIMBER, Division of Mental Health & Mental Retardation, 878 Peachtree St., NE, Atlanta, GA 30309 (404) 894-6313

ID Not available

KY SENATOR ED O'DANIEL, 333 East Main St., Springfield, KY 40069 (606) 335-3901

ME LINDA PIERCE, Dept. of Mental Health & Retardation, 411 State Office Building, Station 40, Augusta, ME 04333 (207) 289-4242

CARROLL MACGOWAN, Pineland Center, Box C, Pownal, ME 04069

MN STEPHEN SCOTT, Legal Advocacy for Persons with DD, 323 Fourth Ave., S., Room 222, Minneapolis, MN 55415 (612) 338-0968

NH Not available

NC No response

OR HOLLY ROBINSON, Oregon Advocacy Center, 625 Board of Trade Bldg., 310 SW Fourth Ave., Portland, OR 97204 (503) 243-2081

UT Not available

VT WILLIAM REEDY, VT DD Law Project, 12 North St., Burlington, VT 05401 (802) 863-2881

VA BRYAN LACY, Dept. for Rights of Disabled, 101 N. 14th St., 17th Floor, Richmond, VA 23219 (804) 225-2042

SHIRLEY RICKS, Dept. of MH & MR, P.O. Box 1797, Richmond, VA 23214 (804) 786-3921.

WV RICHARD KELLY, DD Planning Council, 1800 Washington St. East, Charleston, WV 25305 (304) 348-2276

APPENDIX C

STATE COUNCIL ON DEVELOPMENTAL DISABILITIES

SUBSTITUTE CONSENT FOR STERILIZATION

POLICY ADOPTED OCTOBER 15, 1982

POLICY:

Because the right to procreate is a fundamental constitutional right, the government must have a compelling reason to infringe upon that right for persons declared, by a court, unable to provide informed consent and must do so with laws which are in the best interests of the persons whose rights are being threatened. While there may be numerous assumed justifications for performing sterilizations, the law must define those rare and unusual cases wherein sterilization is considered to be an appropriate procedure. These laws must require that specific standards be met and stringent procedural safeguards be accorded in order to maximally protect the person's fundamental rights. Specific standards shall require, but not be limited to:

a. Evidence that all lesser restrictive alternatives to the sterilization have either been attempted and failed, or are medically contra-indicated.
b. Evidence that the person is capable of procreation.
c. Evidence that the person is not infertile and sexually active.
d. Evidence that the person would suffer severe physical or mental harm if he/she were to parent a child.
e. Evidence that the sterilization would not cause physical or mental harm.
f. Evidence that the person agrees to, or is incapable of indicating approval or disapproval for the sterilization.
g. Evidence that the person's capability to develop, in the foreseeable future, is not likely to change his/her ability to make an informed decision with regard to sterilization.
h. Evidence that the medical risks of the procedure are minimal and medically acceptable.
i. In addition, the court should not assume that an individual who is incapable of giving informed consent cannot adequately raise a child. Evidence must show this to be true.

CONTINUED . . .

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ATTACHMENT 2

Once specific standards are assured, the law must detail a procedure by which the court could authorize a sterilization, and must include stringent procedural safeguards in order to assure the person's right to due process. Such safeguards shall include, but not be limited to:

a. The court appointment of a guardian ad litem to ensure impartial representation of the individual.
b. The appointment of a legal counsel to represent the person for whom sterilization is sought.
c. A legal procedure that assures the maximum privacy to the individual and their family and diminishes outside influences on the procedure.
d. A description of the medical procedure to be used, and answers to any questions the person may have.
e. The individual requesting the sterilization must be able to show that she/he has regular and continuing contact with the person for whom sterilization is sought and, if not an immediate family member or guardian or conservator of the person, has a similar, primary relationship with that person.
f. Persons must have unlimited ability to petition the court for re-hearings on the issue of their sterilization.
g. Persons unable to give informed consent for the purposes of sterilization should not automatically be presumed incompetent for any other purposes.
h. Persons for whom sterilizations are proposed should have the right to independent evaluations at no cost to the person.
i. The judge should meet privately in person with the person for whom sterilization is recommended.
j. Susequent petitions for sterilization should not be allowed to be filed for at least one year after the initial petition was denied.
k. Substituted consent for sterilization should apply to adults only.
l. Specific time limits should be set forth for all evalnative reports to avoid unnecessary delays and uncertainty.

NOTE: The specifics addressed in this policy statement are not designed to be inclusive of all standards or procedural safeguards that should be included in statutes which address involuntary sterilizations; however, these are items which provide maximum protection for the person's right to privacy and may be overlooked in legislative mandates.

APPENDIX D

ORS Chapter 436
A LAY-PERSON'S GUIDE TO
OREGON'S NEW STERILIZATION STATUTE

1. Why did the Oregon Legislature enact a new sterilization statute?

(a) Because sterilization procedures are highly intrusive, generally irreversible and of great consequence to the person, legal safeguards were required to prevent indiscriminate and unnecessary sterilization of persons incapable of giving informed consent;

(b) ORS 436.010, which created a State Board of Social Protection, was inoperative, and no other process existed to legally obtain consent for persons incapable of giving informed consent to sterilization;

(c) Persons who lacked capacity to give informed consent were thus precluded from obtaining sterilizations;

(d) To insure equal access to medical care, the legislature preferred that a decision be made on behalf of an incompetant person, rather than preclude the person's right to obtain sterilization;

(e) To insure that the wishes of the person capable of giving informed consent are respected, regardless of whether others might think that the decision is not in his or her best interest;

(f) To prevent the sterilization of children unless the child is at least 15, is capable of informed consent, and does consent.

2. What is "sterilization"?

The act defines "sterilization" as "any medical procedure, treatment or operation for the purpose of rendering a person permanently incapable of procreating". Sterilization is considered to be a voluntary, rather than medically necessary, procedure. Because the act requires the least intrusive method of sterilization which conforms with standard medical practices, the primary methods of sterilization are likely to be tubal ligation and vasectomy. The act prohibits sterilization by hysterectomy. The act also prohibits hysterectomies performed for the purpose of hygiene or sanitary care during menstruation.

"Sterilization" does not include surgical procedures such as a hysterectomy, which are medically indicated for other purposes and which may result in sterilization.

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For example, the act would permit a hysterectomy to treat uterine cancer or radiation to treat testicular cancer, even though the procedure would result in sterilization.

3. What does "informed consent" mean?

The right to procreate is a fundamental right protected by the First, Fourth and Fourteenth Amendments to the United States Constitution. Before a constitutional right may be waived, the person waiving that right must give informed consent. The constitutional test for informed consent requires consent to be given,

(1) Knowingly - that is, the person must be given all the information necessary to make an informed decision. To satisfy this element, the act requires a physician to give the person seeking sterilization the following information or advice. All of this information or advice must be given orally.

(a) That the person is free to withhold or withdraw consent at any point prior to the sterilization without affecting future rights to care and treatment;

(b) The availability and description of alternate methods of family planning and birth control;

(c) That sterilization is considered to be irreversible;

(d) A thorough explanation of the specific sterilization procedure to be performed;

(e) The discomforts and risks that may accompany or follow sterilization, including the type and possible effects of any anesthetic to be used; and

(f) The benefits or advantages that may result from sterilization.

Further, the physician must offer to answer any questions the person has about sterilization.

(2) Voluntarily - that is, without undue influence or coercion. To satisfy this element, the act requires that informed consent be given "wholly voluntarily and free from coercion, express or implied". For example, pressure from parents, group home providers, or other family members may be considered to be coercive. The act further states that informed consent may not be obtained while the person to be sterilized is:

(a) in labor or childbirth;

(b) seeking to obtain or obtaining an abortion; or;

(c) under the influence of alcohol or drugs that affect the person's awareness.

(3) Intelligently - that is, having an understanding of the right being waived and probable consequences. The standard is not whether others agree, but whether the person is able to weigh the information and make an informed decision. To satisfy this element, the act requires:

(a) that the person fully understands the information given by the physician, and

(b) that the person be "competent" to make a decision such as sterilization.

Competency is the most problematic of the three components. Competancy may be defined with respect to

(a) the person's age;

(b) specific situations (standards may be different for determining competency to stand trial, to consent to sterilization or other medical procedures, to enter into a contract, or to make a valid will);and

(c) the person's physical or mental capacity, the impairment of which can lead to a judicial declaration of incompetancy and appointment of a guardian. However, a person who has been adjudicated incompetent, and for whom a guardian has been appointed, might be found competent for the purpose of consenting or withholding consent to sterilization.

4. What happens if the attending physician believes that the person is capable of giving informed consent?

If the person is not yet 15, a sterilization may not legally be performed.

If the person is at least 15, is capable of giving informed consent, and consents to sterilization, the sterilization may be performed.

If the person is at least 15, is capable of giving informed consent, and refuses consent, the sterilization must not be performed.

There is no procedure for obtaining permission by a Court for sterilization of a person who is capable of giving informed consent.

A parent, guardian or conservator may not give consent for sterilization of his or her minor child or ward.

5. What happens if the attending physician believes that the person seeking sterilization is incapable of giving informed consent?

Someone may file a petition for a determination of the person's ability to give informed consent.

A petition may be filed by the person seeking sterilization, the attending physician, or a person concerned with the health and well-being of the person for whom sterilization is sought.

The petition may be filed in the Circuit Court of the County in which the person for whom sterilization is sought lives.

6. What must the petition contain?

(a) The name, age and address of the person for whom sterilization is sought;

(b) The names and addresses of the person's parents, spouse, legal guardian or conservator, if any;

(c) The facts describing the person's suspected capacity or incapacity to give informed consent for sterilization;

(d) If the person is believed to be incapable of giving informed consent, facts describing the likelihood, if any, that the person will become capable of informed consent "in the foreseeable future";

(e) The reasons why sterilization is sought;

(f) The name, position and interest of the person initiating the petition or any person assisting the person seeking sterilization with a self-initiated petition.

7. What happens after the petition is filed?

The court will schedule a hearing within thirty days. If the person for whom sterilization is sought would have difficulty attending a hearing at the courthouse, the court may hold the hearing at some other place.

At least fourteen days before the hearing date, the court must serve a copy of the petition and hearing notice on:

(a) the person for whom sterilization is sought;

(b) the person's parents, legal guardian or conservator, if any;

(c) If there are no living parents, then to the person's sibling, if any;

(d) The person's spouse, if any;

(e) The Oregon Developmental Disabilities Advocacy Center (ODDAC); and

(f) Other persons that the court determines have an interest in the person.

8. When is the person for whom sterilization is sought entitled to a court appointed attorney?

The court must appoint "suitable counsel possessing skills and experience commensurate with the nature of the petition and the complexity of the case":

(a) at the person's request, or

(b) if the person does not have an attorney and seems incapable of asking for one.

If the court appoints counsel and the person is "without sufficient means",the court will pay "compensation for counsel and reasonable expenses of investigation, preparation and observation", which includes the costs for expert witnesses.

The act also provides for counsel to be appointed on appeal at court expense, if necessary.

The court has no authority to appoint an attorney for anyone other than the person for whom sterilization is sought, such as parents or guardians.

9. Must the person for whom sterilization is sought be present at the hearing?

Yes. However, the right to be present may be waived by the person or the person's attorney, but only if the person's presence:

(a) grossly interrupts the proceeding, or

(b) is medically unadvisable.

10. What happens at the hearing?

The hearing consists of a two-step process. The first step of the hearing is to determine whether the person is capable of giving informed consent.

The person filing the petition will present evidence which must include reports by a team of at least three professionals,

representing at least two different disciplines. All three professionals must have experience with persons who have disabilities similar to the disability of the person for whom sterilization is sought. The professionals may include teachers, doctors, social workers, mental health workers and other health professionals.

The reports must contain:

(a) the aspects of informed consent of which the person is capable;

(b) the aspects of informed consent of which the person is not capable; and

(c) the reasons for each opinion.

The person for whom sterilization is sought may present evidence and cross-examine witnesses. Witnesses may be subpoened, if necessary.

At the time of the hearing, the court must inquire as to the types and effects of any medications taken by the person for whom sterilization is sought.

11. How does the judge decide whether the person is capable of giving informed consent?

A judge can find a person incapable of giving informed consent only by "clear and convincing evidence". In other words, the judge must find it highly probable from the evidence that the person lacks ability; otherwise, the person will be found capable of giving informed consent.

This standard is higher than the general standard in civil cases which is by a "preponderance of evidence", or more probable than not. However, it is lower than the standard used in criminal cases, which is "beyond a reasonable doubt". The "clear and convincing" standard is adopted when there is a special danger of deception or when a particular result is disfavored on policy grounds.

12. What happens if the judge decides that the person is capable of giving informed consent?

If the person consents, the court will issue an order permitting sterilization. The hospital and doctor must still obtain written consent prior to the sterilization.

If the person refuses, the court will issue an order forbiding sterilization. If a person refuses, and then consents at a later date, a rehearing must be held.

13. What happens if the judge decides that the person is not capable of giving informed consent?

If the person is younger than 18 years old, the hearing is concluded. The court has no authority to substitute consent for persons younger than 18. Parents and guardians have no authority to consent to sterilization for their child or ward. Thus, sterilization may not be performed on persons who are not yet 18 and incapable of giving informed consent.

If the person is 18 years or older, the second step of the hearing is to determine whether sterilization is in the person's "best interest".

14. What factors determine whether sterilization is in a person's "best interest"?

The act sets out five factors:

(a) The person is physically capable of procreating;

(b) The person "is likely to engage in sexual activity at the present or in the near future" which is likely to result in pregnancy;

(c) "All less drastic alternative contraceptive methods, including supervision, education and training, have proved unworkable or inapplicable", or are medically unadvisable;

(d) The method of sterilization to be used:

- conforms with standard medical practice;
- is the least intrusive method available and appropriate (e.g. hysterectomy may not be performed for the purpose of sterilization or hygiene);
- may not create an unreasonable risk to life and health of the person.

(e) Due to the nature and extent of disability, the person is permanently incapable of caring for and raising a child, even with reasonable assistance. The nature and extent of disability cannot be solely determined by standardized tests (e.g. IQ tests), but must be based on empirical evidence.

15. What happens at Step II of the hearing?

The person seeking sterilization must present evidence which proves that the person for whom sterilization is sought meets each of the five factors.

Evidence must include opinions by a doctor, a psychologist and a social worker.

The person for whom sterilization is sought may present evidence and cross-examine witnesses.

16. How does the judge decide whether sterilization is in the person's best interest?

The judge must find by clear and convincing evidence that sterilization is in the person's best interest. In other words, for each factor, the judge must find it highly probable that the factor is satisfied. If the judge does not find enough evidence on any one factor, sterilization will not be found to be in the person's best interest. (See Question 11 for further explanation.)

17. What happens if the judge finds that sterilization is not in the person's best interest?

The judge will issue findings to support that conclusion. The judge will also issue an order prohibiting sterilization.

18. What happens if the judge finds that sterilization is in the person's best interest?

The judge will issue findings to support that conclusion. The judge will also issue an order permitting sterilization.

A GUIDE TO ORS CHAPTER 436 - OREGON'S NEW STERILIZATION STATUTE

A TWO STEP PROCESS

	Age Requirements	Procedural Prerequisites	Hearing	Test	Standard	Outcome
STEP I INFORMED CONSENT	15 years old ORS 436.225 (3)	File petition with necessary information ORS 436.235-.245 Court notifies necessary parties ORS 436.255 Alternative location, if necessary; counsel appointed, if necessary ORS 436.255-.265	Person present unless waived ORS 436.285 Evidence by 3 professionals-2 disciplines ORS 436.275(1) Inquiry regarding medication ORS 436.285 Witnesses subpoened; cross examination ORS 436.275(2)-.275(3)	Informed Consent: *Knowingly *Intelligently *Voluntarily ORS 436.205(2)	Clear and convincing evidence ORS 436.295	Capable of informed consent ORS 436.295(1) If consent given, sterilization permitted If consent refused sterilization prohibited. Not capable of informed consent ORS 436.295(2) Go to Step II
STEP II BEST INTEREST	18 years old ORS 436.225(3)	As a result of Step I, judge finds person not capable of giving informed consent. May be continance of same hearing. ORS 436.295(2)	Person present unless waived ORS 436.285 Evidence by physician, phychologist, social worker. ORS 436.305(1) Witnesses subpoened; cross-examination. ORS 436.305(2)	Best Interest: *Capable of procreating *Sexually active *Alternatives exhausted *Least intrusive method *Permanently incapable of caring for child even with assistance.	Clear and convincing evidence ORS 436.305(3)	In Best Interest Court permits sterilization ORS 436.306(3) Not in Best Interest Sterilization prohibited. ORS 436.305(3)

APPENDIX E

WHEN PARENTS CONSIDER STERILIZATION FOR THEIR SONS OR DAUGHTERS WHO ARE MENTALLY RETARDED

Prepared by a Task Force
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FOREWORD

The intent of this paper is to provide basic information about sterilization, the legal status of sterilization as it affects people who have mental retardation, and to bring to the fore some of the questions which should be given careful thought when sterilization is being considered.

Readers should know that there is constant progress being made in the development of techniques used for sterilization. Some forms of sterilization are reversible. Also, court law is rapidly changing the legal status of sterilization. These facts may make parts of this paper rapidly obsolete.

On behalf of the Association for Retarded Citizens Minnesota, I wish to thank the members of the Task Force who worked on the development of this paper. They represented a broad base of people knowledgeable about the subject, including parents.

Special thanks goes to Evelyn Anderson and Sally Swallen of the ARC Minnesota staff, for putting people's ideas and thoughts into written words, and for coordination; to Rebecca Knittle and Patricia Suita of the Legal Advocacy Project for the section on the legal aspects; to Miriam Ruben of the Association for Voluntary Sterilization in New York and Shirley Bengtson of the Minnesota Division of Mental Retardation for the materials and suggestions they submitted; and finally to Tineka Messinger, who chaired the Task Force and saw the project through to finalization.

We hope this paper will be helpful to many people who have mental retardation and their families.

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ATTITUDES TOWARD SEXUALITY

Most parents have mixed feelings as their teenagers and young adults develop sexually. They wonder if their sons or daughters are mature enough to make what the parents consider to be the right decisions. They worry about the young peoples' choice of friends. They wonder if they have given the young people enough information, in the right ways.

Parents of young people who are mentally retarded share these feelings and may have some added concerns. They may observe that their teenagers' sexual growth and interests are keeping pace with those of other young people the same age. Parents may be concerned about their son's or daughter's mental and emotional ability to deal with sexual feelings. Parents may be concerned about their young person's vulnerability and may fear that he or she will be hurt by others, or teased.

Some parents, accustomed to thinking of their mentally retarded teenagers as younger than their actual age, may want to continue to shield their children from experience with the opposite sex, or from knowledge of sex. In a well-meaning effort to protect the young person, the parents may deny him or her the information needed to deal with normal sexual interests.

As any young person shows an interest in physical sex, his or her family may begin to give thought to the possibility of the boy fathering a child or the girl becoming pregnant.

The mass media express with great appeal our society's interest in sexuality and in family life. Through advertisements, movies, television programs, and many other sources, young people who are mentally retarded are learning that sexual needs are a major part of life. They also learn that being married and having children is an ideal that many people adopt. Quite naturally, the young person who is mentally retarded may want the same thing.

In all aspects of life, parents and professionals today try to treat the person who is mentally retarded as an individual. The unique abilities, interests and lifestyle of each mentally retarded person should be considered when decisions are made, just as differences are taken for granted in the general population.

Individual differences also extend to a person's sexuality. Some mentally retarded persons will be sexually active; others will not be. Some will have no desire to become parents; others will. Some will be able to express affection in happy, healthy and fulfilling ways; others will need help in learning this. Some will be able to use birth control of various types; others will not be able to...will not need to... or will not want to. Some will have an interest in dating and marriage; others will not.

BIRTH CONTROL

Like other young people, those who are mentally retarded should receive meaningful programs of sex education that deal with the emotional as well as the physical aspects of sexuality. If they are likely to become sexually active, young people who are mentally retarded should be counseled individually about the various forms of contraception, when appropriate, to help them understand and make choices.

(For more information on birth control methods, contact your family physician and/or other family planning resources.)

Only after serious consideration, plus trial usage of less final forms of birth control, should sterilization be considered. While it is often an irreversible method of birth control, it should be pointed out that sterilization is becoming the method of choice for many American men and women. It should also be considered that there is possibility of risk to one's health when, using the birth control pill for an extended period of time.

WHAT IS STERILIZATION?

Sterilization is a method of conception control, achieved surgically, by closing a pair of small tubes in either the man or the woman so that the sperm and egg cannot meet. Sterilization is not an everyday occurrence. It is a procedure which should be considered as permanent.

Sterilization is not castration. It does not involve removal of any gland or organ and usually has no unfavorable effect on a person's sex life.

Sterilization for the male (vasectomy) can be done in a doctor's office under local anesthesia. The traditional operation for a woman (salpingectomy) may require four or five days hospitalization. Another method (laparoscopy) requires only one or two "band-aid sized" incisions and frequently is performed without an overnight stay in the hospital. The newest method (mini-laparotomy) can be performed in 10-30 minutes and women can be discharged the same day.

WHY MIGHT STERILIZATION BE CONSIDERED?

A number of factors might cause a person who is mentally retarded, or his or her family, to consider sterilization:

(1) Desire not to have children

(2) Inability to care for a child

(3) Inability to use other means of birth control

(4) The risk and/or major discomfort of other methods of birth control

Sometimes the difficulty a young girl has in coping with menstruation may bring her parents to consider a hysterectomy (removal of the uterus) to stop menstruation. In most cases, however, education and training can help the girl understand and manage menstruation. Major surgery to alter normal body function is not likely to be approved for a person who is not of age.

Whatever the reason for considering sterilization, the persons involved in the decision should carefully consider their own feelings and assumptions. Would additional education be helpful? Might so final a decision be regretted later? In making such a decision, it should be remembered that all people, including those who are mentally retarded, will change, grow and develop throughout their lives.

FERTILITY RATE

It is not wise to speak in a general way about the fertility rate of people with mental retardation. It is very possible for many retarded women to conceive and retarded men to impregnate. Some syndromes do have a lowered fertility rate. For example, no fully affected man with Down's Syndrome has been known to father a child. Babies have, however, been born to women with Down's Syndrome, including normal babies, Down's Syndrome babies and babies with other forms of retardation. Each individual's likelihood of fertility depends on a number of factors, including the particular cause of his/her mental retardation. Therefore, the need for, and appropriateness of contraceptive measures or sterilization are issues which can only be answered for each individual after evaluating that individual and his/her environment.

WHAT IS THE LAW REGARDING STERILIZATION?

In recent years, Minnesota has adopted laws that attempt to protect the mentally retarded person from involuntary sterilization and at the same time guarantee that person the right to sterilization when it is wanted and needed.

PERSONS WHO ARE UNDER PUBLIC GUARDIANSHIP OR CONSERVATORSHIP OF THE COMMISSIONER OF PUBLIC WELFARE

Only a small percentage of the mentally retarded persons in Minnesota are under public guardianship or conservatorship. Their rights are covered under the 1975 Mental Retardation Protection Act. Minnesota Statutes Chapter 252A. Subject to court approval, the Commissioner has the power to consent to the sterilization of a public ward and of a public conservatee whose right to consent to sterilization has been restricted. M.S.A. 252.11 subd. 1(f). For conservatees, competency to consent to sterilization is determined at the initial hearing for appointment of a conservator. Public conservatees found competent to consent to sterilization may be sterilized only if they consent to the operation. M.S.A. 252.13 Subd. 3. This consent must be in writing or there must be a sworn statement by an interested person that the mentally retarded person consented orally. The consent form must state that the mentally retarded person has received a full explanation from a physician or registered nurse of the nature and irreversible consequences of the sterilization operation.

State wards and conservatees found incompetent to consent to sterilization may be sterilized only if (a) the Commissioner consents, and (b) if the ward is a minor, his parent or nearest relative consents, and (c) a court, after a hearing at which the ward or conservatee is represented by an attorney, determines that sterilization is in the person's best interest. The Commissioner must provide the court with reports from a physician, a qualified psychologist and a social worker. The medical report must consider the medical risks of sterilization and whether alternative methods of contraception would be as effective in protecting the best interest of the ward or conservatee. M.S.A. 252A.13 subd. 4.

ADULTS UNDER PRIVATE GUARDIANSHIP OR CONSERVATORSHIP

A private guardian, or a conservator although given the power to consent to medical treatment, may not give consent for sterilization unless the sterilization is first approved by order of a court, after the same type of hearing described above. A guardian or conservator of the estate has no power to consent to the sterilization of a ward or conservatee.

MENTALLY RETARDED PERSONS NOT UNDER GUARDIANSHIP

Minors - The status of the parent's power to consent to the sterilization of a minor child is in doubt at the present time. Some authority suggests that the parents or guardian can never have sole power to consent to a sterilization operation for a minor child. Recent cases in other jurisdictions reflect a trend in favor of preventing parents from consenting to sterilizations for their minor children. The United States and Minnesota Supreme Courts have not yet issued a definitive decision in this very difficult area. There are no present Minnesota Statutes governing the authority of parents to consent to the sterilization of their minor children.

Adults - Most Minnesota hospitals require that before any operation is performed, including sterilizations, a legally-effective consent form be completed. Presently, there are no specific state laws giving us assistance in determining what is legally effective.

The Federal Department of Health and Social Services has regulations regarding sterilization under federal assistance programs:

(A) Preparing to Obtain Informed Consent - An individual who obtains informed consent for a sterilization procedure must provide orally all of the following information or advice to the individual who is to be sterilized.

(1) Advice that the individual is free to withold or withdraw his/her consent to the procedure at any time prior to the sterilization without affecting his/her right to future care or treatment, and without loss or withdrawal of any federally-funded program benefits to which the individual might be otherwise entitled;

(2) A description of available alternative methods of family planning and birth control;

(3) A full description of the benefits or advantages he/she may expect to gain as a result of the sterilization;

(4) Advice that the sterilization procedure is considered to be irreversible;

(5) A thorough explanation of the specific sterilization procedure to be performed;

(6) A full description of the discomforts and risks which may accompany and follow the performing of the procedure, including an explanation of the type and possible effects of any anesthetic to be used;

(7) Advice that the sterilization will not be performed for at least 30 days;

(8) An opportunity to ask and have answered any questions he/she may have concerning the sterilization procedure.

(43 Federal Register 52146,
November 8, 1978.)

It would seem reasonable for these regulations to be viewed as a guideline in determining whether or not a mentally retarded adult has given an informed, knowing, voluntary and legally-effective consent to the sterilization operation.

IF MY SON OR DAUGHTER WERE TO BECOME A PARENT, WOULD THE CHILD BE MENTALLY RETARDED?

The "laws" of genetics carry no guarantees, either for a child to be born normal or to be born handicapped. Most mentally retarded children are born to parents who are not mentally retarded.

Genetic counseling, however, can help a person understand the risks or probabilities and make an informed decision about conceiving a child. In addition, recent developments in prenatal care, including detection and treatment of problems, can assist both parent and child should pregnancy occur.

WOULD MY SON OR DAUGHTER BE ABLE TO RAISE A CHILD?

Many mentally retarded adults lack the mental and emotional resources to raise a child. All persons considering parenthood should be aware of the responsibilities it entails. Some mentally retarded persons have raised children successfully and some have not.

Factors such as the potential parent's emotional maturity, the possible family's stability, and the potential parents' desire to help a child develop may be as important to parenting as the level of intellectual functioning. Parents who are mentally retarded may need to make special efforts to see that their children receive the necessary stimulation. A number of programs have been developed to help parents, such as counseling services, homemaker and visiting nurse services, day care, developmental achievement programs and infant stimulation programs. It might be helpful to determine whether such services are available to the family in the community where they live.

The decision to become a parent should be evaluated individually, by the person himself or herself and family members. The person's own desires and the well-being of any future children should be considered carefully and seriously.

IS THERE SOMEONE WE CAN TALK TO ABOUT THIS DECISION?

First, of course, parents should discuss the matter with the young person who is mentally retarded. He or she should be aware of the reasons why sterilization might be considered, and the other alternative forms of birth control.

Parents and young people together should consider questions like these:

(1) What does the young person want? How can he or she be helped to make decisions regarding birth control or responsible sexual behavior?

(2) Is the young person able to use birth control? Which kind or kinds - - what are the risks of various types of birth control for the particular individual?

(3) Has the young person had outside help and advice? Has he or she received sex education and counseling?

(4) Does the young person wish to raise a child, and is the wish to rear a child realistic?

(5) Is this the right time to consider sterilization? Could anything happen later to make us regret the decision?

(6) Could the young person give informed, knowledgeable, voluntary consent to sterilization?

A number of outside resources are available to help families make these decisions. Parents may wish to talk to other parents who have faced the same decision. Young people may want to talk to other persons who have faced the same decision.

Family counseling is available through some county welfare and health departments, the larger ARCs and area mental health/mental retardation programs.

Planned Parenthood conducts workshops for parents and professionals on sexuality and mentally retarded persons. It also publishes a variety of literature and distributes films. Speakers may be available for ARC or other meetings. Planned Parenthood has offices in the Twin Cities, Bemidji, Duluth, Mankato, Rochester, Brainerd and Willmar.

Genetic counseling services are available through the Minnesota Department of Health in minneapolis and in a number of other communities.

SUMMARY

The decisions faced by persons who are mentally retarded and their families regarding contraception are difficult. Our society is beginning to recognize the rights of persons who are mentally retarded to a normal expression of their emotional needs. That means we now must make a greater effort to educate young people who are mentally retarded about the responsibilities and risks of sexuality, as well as its joys.

It is not appropriate to make a decision one way or another simply because a person is mentally retarded. Whatever decision is made should be based on the individual... his or her needs, abilities, desires and maturity, as well as level of mental retardation.

Voluntary sterilization is one of several alternatives available today to persons who are mentally retarded as they plan the kind of life they want to lead; however, sterilization should be considered a final decision.